

Quality of life in young adults with ASD: Exploring the role of anxiety

Isaac C. Smith

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Susan W. White, Committee Chair  
Thomas H. Ollendick  
Jungmeen Kim-Spoon

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### ABSTRACT

The comorbidity of anxiety disorders and autism spectrum disorder (ASD) is well-established. Although research on the comorbidity of anxiety disorders in adults with ASD is limited, preliminary studies suggest rates of comorbidity comparable to those found in children and adolescents. Little is known about the manifestation of anxiety symptoms in adults with ASD or the potential for these symptoms to impact quality of life in this population. The current study aimed to examine the role of anxiety symptoms in quality of life among young adults with ASD. We collected online survey data from a large sample ( $N = 224$ ) of parents of young adults with ASD and a subsample of adults with ASD. Parent- and self-report data suggested a substantial proportion of adults with ASD exceeded clinical cutoffs for anxiety symptoms. Anxiety moderated the relationship between ASD severity and the social relations domain of quality of life. Anxiety symptoms did not, however, significantly moderate the effect on the psychological domain. Exploratory analyses also demonstrated significant indirect effects of ASD severity on social and psychological quality of life through anxiety symptoms. Results provide preliminary evidence that anxiety symptoms contribute to quality of life in adults with ASD independently of core ASD symptomatology. Future research should aim to further characterize anxiety symptoms among adults with ASD, as well as evaluate the impact of anxiety symptoms on quality of life and overall outcome through the use of prospective longitudinal studies.

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### **Introduction**

Autism Spectrum Disorder (ASD) is characterized by marked deficits in social communication and the presence of restricted and repetitive behaviors (American Psychiatric Association, 2013). The prevalence of ASD has risen dramatically over the past 20 years, with estimated rates now as high as 1 in 68 (CDC, 2010). In addition to difficulty with the core symptoms of social communication and restricted and repetitive behaviors, individuals with ASD frequently present with comorbid anxiety symptoms (van Steensel, Bogels, & Perrin, 2011). The comorbidity of anxiety and ASD has been studied extensively in children and adolescents. A substantial body of literature has established rates of comorbidity in the range of 50%. Anxiety disorders frequently found in adolescent samples with ASD include social anxiety disorder (SAD) and generalized anxiety disorder (GAD; White, Oswald, Ollendick, & Scahill, 2009). Anxiety symptoms frequently form the focus of treatment in children and adolescents. Such treatments have been demonstrated to be effective, with interventions having positive effects on social skills as well as anxiety symptoms (Maddox, Miyazaki, & White, 2016).

### **Comorbidity in Adults with ASD**

Despite the extensive body of literature documenting the comorbidity of anxiety and ASD in children and adolescents, anxiety in adults with ASD is an understudied area. Preliminary studies suggest that anxiety symptoms are at least as common in adults with ASD as in children and adolescents. Lugnenard and colleagues (2011) found that over half (56%) of a sample of 54 young adults with ASD met diagnostic criteria for at least one anxiety disorder. Another study (Maddox & White, 2015) determined that SAD was present in 50% of a non-clinically referred sample of adults. Adults with ASD have also been demonstrated to exhibit

significantly more anxiety symptoms than comparison samples with intellectual disability (Gilliot & Standen, 2007).

### **Outcome in Adults with ASD**

Outcome and quality of life as they relate to ASD refer to broad constructs, which have in previous research included levels of education and employment, independent living skills, social relationships, and person-environment fit (Henninger & Lounds-Taylor, 2013). Though the prognosis for individuals diagnosed with ASD has historically been poor, more recent evidence suggests improvement, with a higher proportion of individuals diagnosed at higher levels of cognitive ability and a greater proportion of individuals completing postsecondary education, participating in competitive employment, and living independently (Howlin, 2000). Despite these improvements, however, recent research regarding outcomes has demonstrated that, relative to people who have ASD and cognitive impairment, more cognitively able individuals with ASD experience generally poor outcomes. Taylor and Mailick (2014) found that young adults with ASD actually suffer from decreasing independence as they enter adulthood, with lower rates of competitive employment and increased likelihood of dropping out of postsecondary education. The majority of studies examining employment in samples of adults with ASD have reported that a minority of adults with ASD are engaged in any type of employment (Ballaban-Gil, 1996; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Taylor & Seltzer, 2011). For those who do work, underemployment is a substantial problem, as positions held are rarely competitive in nature, and wages and hours worked are low (Ballaban-Gil, 1996).

In addition to those studies examining objective indicators of outcome (e.g., education, employment), some studies have explored subjective ratings of quality of life among adults with



ASD. Though extant research in this area is limited, the available evidence indicates that quality of life is lower among individuals with ASD than in typically developing samples. In child samples, individuals with ASD were demonstrated to have lower quality of life in the domains of total, psychosocial, emotional, and social functioning as compared to samples with chronic health conditions (Kuhlthau et al., 2010). Families of children with ASD have lower quality of life than both families of children with ADHD and typically-developing controls (Lee, Harrington, Louie, & Newschaffer, 2008). Parallel results have been demonstrated in adults with ASD. A sample of adults with Asperger syndrome reported significantly lower social and physical quality of life than a control group, despite comparable living situations, numbers of friends, and levels of education (Jennes-Coussens, Magill-Evans, & Koning, 2006). One study identified a disconnect between more frequently used objective metrics and subjective quality of life; quality of life and well-being were rated highly despite a lack of overall independence and a strong reliance on caregivers for the provision of accommodation, obtaining of services, and financial support (Billstedt, Gillberg, & Gillberg, 2011). However, this sample is likely not representative given that severe and profound intellectual disability were overrepresented.

Current research has explored a number of contributors to poor outcome and quality of life in adults with ASD. Perhaps not surprisingly, both ASD symptom severity and cognitive ability in childhood have emerged as the strongest predictors of positive outcome in adulthood (Anderson, Liang, & Lord, 2014; Eaves & Ho, 2008; Howlin et al., 2004). Adaptive functioning has also been associated with improved outcome, as has the presence of formal (i.e., professional services) and informal (i.e., help from relatives) disability support (Kanne et al., 2011; Renty & Roeyers, 2006). These results have been demonstrated across a number of large-scale,

prospective longitudinal studies, with first evaluations occurring early in life (Szatmari, Bryson, Doyle, Streiner, & Duku, 2003).

### **Anxiety as a Predictor of Outcome in ASD**

Although the factors described above have been found to contribute significantly to outcome, additional evidence suggests that anxiety symptoms likely represent another critical contributor, and one that has been neglected in the current outcome literature. Anxiety has been established as a significant contributor to poor quality of life in samples without ASD. A meta-analytic study examining quality of life across anxiety disorders (SAD, panic disorder, post-traumatic stress disorder, GAD, and obsessive-compulsive disorder) found large effect sizes indicative of lower quality of life for individuals with anxiety disorders compared to control groups (Mendlowicz & Stein, 2000; Olatunji et al., 2007). Results specific to SAD have demonstrated that individuals with that disorder are more likely to suffer from impairment in their main activities and to rate their quality of well-being lower than individuals without SAD (Stein & Kean, 2000). Similar evidence has been found in other studies of social and generalized anxiety and quality of life (Simon et al., 2014; Henning et al., 2007).

ASD and anxiety may both predict poor quality of life in part due to shared transdiagnostic processes. The role of emotion regulation, or effortful control of emotional responses in order to facilitate adaptive or goal-directed behavior, has been examined in both anxiety and ASD. Emotion regulation has been implicated in the development of child anxiety disorders and proposed as a factor limiting the effectiveness of treatment (Hannesdottir & Ollendick, 2007). Recent literature has begun to explore the role of emotion regulation in ASD and identified components of emotion regulation likely unique to ASD as well as shared processes (Mazefsky et al., 2013). To this end, emotion regulation has been proposed as a risk

factor for the development of comorbid anxiety among individuals with ASD (White et al., 2014).

These common etiological processes have led some researchers to express doubt that anxiety symptoms as manifested in ASD can be distinguished from core ASD symptomatology. Many symptoms typically associated with anxiety disorders offer the potential to be attributed to core ASD symptomatology rather than a true comorbid manifestation. For example, avoidance of social situations, a core symptom of SAD, might easily be ascribed to poor social skills and low social motivation more frequently associated with autism (Wood & Gadow, 2010). Similarly, intolerance of uncertainty, a core component of many anxiety disorders, shares commonalities with the autistic symptoms of restricted and repetitive behaviors and resistance to change (Rodgers, Glod, Connolly, & McConachie, 2012).

To explore this hypothesis, researchers have attempted to disentangle true anxiety symptoms from core ASD symptomatology. Kuusikko and colleagues (2008) identified features of SAD distinct from those attributable to ASD in a sample of children and adolescents. Other studies have distinguished restricted and repetitive behaviors from obsessive-compulsive symptoms (Simonoff et al., 2008). As a whole, though anxiety disorders frequently present with qualitative differences among individuals with ASD as compared to typically-developing controls, the preponderance of evidence in the literature suggests that ASD and anxiety are separable entities (Kerns & Kendall, 2012). Difficulties associated with the application of existing anxiety assessments to ASD populations have been noted (White et al., 2015), potentially hindering identification of true anxiety symptoms in ASD. Future creation of ASD-specific anxiety measures might facilitate accurate diagnosis of anxiety in individuals with ASD (Kerns et al., 2015).

Given that literature has established that high rates of comorbidity are likely to reflect true presentation of anxiety within ASD (rather than a misattribution of core ASD symptoms), core ASD symptoms are likely to play a role in the development of anxiety disorders among this population. Researchers have proposed that individuals with ASD who make frequent social overtures that are unsuccessful (due in part to poor theory of mind or other ASD traits) may develop an expectation of rejection that ultimately generalizes to a broader fear of negative evaluation (Mazefksy & Herrington, 2012). Within the category of restricted and repetitive behaviors, resistance to change has been demonstrated to increase risk for the development of anxiety disorders in typically developing populations (Muris & Ollendick, 2005); a parallel pathway may well exist in individuals with ASD. Wood & Gadow (2010) proposed a hypothetical model in which core ASD symptoms might increase susceptibility for the development of anxiety disorders. Specifically, individuals with ASD are likely to experience greater levels of negative affect, increased difficulty with emotion regulation, and more frequent unsuccessful social encounters; each of these factors might confer additional risk. Development of clinically significant anxiety symptoms has been proposed, in turn, to affect outcomes for individuals with ASD via a moderating or mediating relationship (Wood & Gadow, 2010).

Further research is needed to more firmly establish the presentation of anxiety disorders in samples of emerging adults with ASD. If clinically significant anxiety symptoms are present in adults with ASD at comparable levels to those that have been demonstrated in children and adolescents, an examination of the extent to which these symptoms contribute to poor quality of life is warranted. To date, no prior research has examined the impact of *both* ASD severity and anxiety in a sample of adults diagnosed with ASD. Given that anxiety disorders and ASD have been found to exert independent, significant negative impact on metrics of quality of life,

comorbid presentation of these two disorders may have synergistic effects. Better understanding the influence that anxiety has on the achievement of positive outcomes may serve to inform treatment of anxiety, ultimately improving long-term functional outcomes for adults with ASD.

### **Present Study**

The purpose of the present study was to determine the extent to which anxiety symptoms negatively influence quality of life in adults with ASD, independent of the impact of core ASD symptoms. To that end, we first sought to explore anxiety symptoms as a moderator of the relationship between ASD severity and quality of life. Second, as a preliminary step to a longitudinal study of anxiety symptoms and outcome in ASD, we aimed to explore the indirect effect of ASD severity on quality of life through anxiety symptoms. While neither of these analyses allows for conclusions to be drawn regarding directionality, much less causality, preliminary evidence for anxiety as a mechanism of outcome would establish rationale for future work in this area, including prospective longitudinal studies that would allow for the consideration of temporal precedence.

### **Hypotheses**

Parallel to the study aims above, we propose the following hypotheses:

1. After controlling for intellectual ability/language impairment and medication status, presence of anxiety will significantly and negatively predict social and psychological quality of life such that individuals with ASD and higher levels of anxiety will experience lower quality of life than those with equivalent ASD severity and low anxiety.
2. After controlling for cognitive ability and medication status, there will be a significant indirect effect of ASD severity on quality of life through anxiety

symptoms such that the strength of the direct path is diminished following the addition of anxiety symptoms to the model.

## **Method**

### **Participants**

Participants for the current study were recruited with the assistance of the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute in Baltimore, MD. IAN is an online volunteer registry of families of individuals with ASD who have indicated interest in participating in research studies. Families enrolled in the IAN registry include a broad range of ages and functioning levels, have at least one child with a confirmed ASD diagnosis provided by a professional, and live in North America. Total enrollment in the registry exceeds 5,000 individuals. Recruitment for the current study was restricted to parents of individuals with autism aged 18-27 years.

Primary respondents included 224 parents of individuals meeting study inclusion criteria and providing complete data. Upon completion of the survey, parents were invited to provide contact information for their adult child (hereafter referred to simply as “adult”) with ASD, who were recruited for the secondary self-report portion of the study. Mean age of adults with ASD fell within the targeted range ( $M = 21.86$ ,  $SD = 2.97$ ). Respondents were primarily male (81%) and Caucasian (93%). Parent respondents reported age ( $M = 53.76$ ,  $SD = 6.70$ ) and level of education (80% completed college or graduate degree). Secondary respondents included 41 adult self-report participants. See Table 1 for complete demographic information.

### **Measures**

*Screen for Anxiety and Related Emotional Disorders (SCARED; Birmaher et al., 1997)*. The SCARED parent-report version was used to screen for anxiety disorders. Parents

rated symptoms of their adult's anxiety on a three-point Likert scale. The SCARED includes subscales for the following types of anxiety: Panic Disorder/Somatic Symptoms, GAD, Separation Anxiety, SAD, and School Avoidance. Adequate internal consistency, test-retest reliability, and discriminant validity of the SCARED have been previously established (Birmaher et al., 1997). The SCARED was normed on a sample of individuals between the ages of 9 and 19; the upper range of this normative sample therefore overlaps with the age range included in the current study (Birmaher et al., 1999). While the SCARED has been used for children up to age 17, items used in the current study were re-worded to upward extend the measure for parent report of adult samples (e.g., "My son/daughter gets headaches when s/he is at school" to "My son/daughter gets headaches when s/he is at school or work"). For those adults completing surveys, a self-report version of the SCARED was included, with items similarly adapted (e.g., modification of items specific to school attendance). Internal consistency for the parent report total score of this measure was  $\alpha = .93$ , and internal consistency for the total score of this measure in the self-report sample was  $\alpha = .96$ .

*The Social Responsiveness Scale, Second Edition (SRS-2; Frazier et al., 2013)*. The SRS-2 relative/other report was completed by parents of adults with ASD. The SRS-2 and its predecessor, the SRS, are among the most well-validated and frequently used measures of ASD severity (Constantino et al., 2003; Frazier et al., 2013). The SRS-2 consists of 65 items with subscales in the domains of social awareness, social cognition, social communication, social motivation, and autistic mannerisms. Internal consistency for this measure was  $\alpha = .95$ .

*World Health Organization Quality of Life-Brief (WHOQOL-BREF; World Health Organization, 1998)*. The WHOQOL-BREF is broadly supported as a reliable and valid measure of quality of life as influenced by physical or mental disability. The measure assesses the

domains of physical health, psychological well-being, social relationships, and environment (e.g., home environment, financial resources, participation in recreation & leisure activities, etc.). The social relationships and psychological domains of both parent- and self-report versions of this measure were used in the current study. These two subscales were most closely linked in theory to anxiety and consistent with prior literature (Kamio, Inada, & Koyama, 2013). Although quality of life is often considered as a unidimensional construct, many facets are present that may contribute to an individual's overall well-being; social and psychological domains include items likely relevant to the experience of adults with ASD. Internal consistency for the parent-report version of this measure was  $\alpha=.91$ , while internal consistency for the self-report version was  $\alpha=.94$ . Internal consistencies for the social relations and psychological subscales of the parent-report version (used for analyses) were  $\alpha=.80$  and  $\alpha=.76$ , respectively.

***Demographic Items.*** In addition to the standardized measures described above, we included a set of demographic questions in order to more accurately characterize our sample. Items related to diagnosis included first diagnosis provided, provider of first diagnosis, age at first diagnosis, and change of diagnosis over time. Items related to level of functioning included use of spoken language, pragmatic language difficulties, and use of assistive communication devices. Education items included highest degree attained and whether adult was currently enrolled in an educational program. Additional questions pertaining to independent living, provision of financial support, use of Social Security Disability Insurance, Medicaid, or state benefits were also included. Finally, we included questions inquiring about number and intensity of friendships, comorbid diagnoses (including anxiety), use of medication, and use of a variety of treatments for either ASD or comorbid diagnoses.



## **Procedure**

Parents of individuals with ASD who had previously registered with IAN and who had adults with birthdates placing them in the 18-27 target age range were emailed an invitation to complete a contact form for the current study. Upon completion of the contact form, a 4-digit randomly generated ID was created for the parent respondent, which was emailed to each parent with a link to the complete survey. Parents who had received invitation emails but had not indicated interest were sent reminders via email at 5 days, 13 days, and 23 days after the initial survey launch. In addition, parents who had been emailed surveys but had not yet completed them were emailed two reminders at approximately one-week intervals. The final email specified that no further contact would be made regarding study participation. The total set of measures completed by parents consisted of demographic items, SRS-2, SCARED, and WHOQOL-BREF. Parents who completed the survey were offered an opportunity to enter a raffle for one of 24 Amazon gift cards valued at \$25.00, with chances of winning estimated at 1 in 9.

Self-report responses were recruited via parents who had completed the initial (primary) portion of the study. Upon completion of the parent-report survey, parents were presented with an adult contact form. Each parent was able to enter contact information (i.e., email address) for up to three of their adults meeting inclusion criteria for the study, should they believe their adult might be interested in completing the study and able to do so. A random 4-digit code was generated for each adult email provided; parent and adult survey codes were connected such that survey responses could be linked. Adults were contacted via email with invitations to complete the study. Two reminder emails were sent to potential adult participants at approximately one-week intervals following the initial invitation to complete the survey. The total set of measures filled out by self-report respondents consisted of the SCARED and the WHOQOL-BREF.

Following completion of the self-report survey, self-report participants were invited to enter their contact information in a raffle for one of 2 Amazon gift cards valued at \$25.00, with chances of winning estimated at 1 in 9.

A power analysis conducted using the G\*Power program (Faul et al., 2009), indicated that for a hierarchical multiple regression with two predictors, an effect size of .01, and alpha set at .10 (given our directional hypotheses), a sample size of 600 would result in power of .70. The effect size used to calculate power was selected based on prior research, as well as guidelines established regarding common effect sizes in moderation analyses (e.g., Cohen, 1992). Given that the base from which we recruited consists of approximately 3500 families, a response rate of approximately 17% would have yielded a sufficiently large sample for the proposed analyses.

### **Data Analytic Plan**

All data were analyzed using IBM SPSS Statistics Version 20.0. Prior to conducting analyses evaluating moderating and potential mediating effects of anxiety, data were screened for normality of distributions, and all distributions were found to have skewness and kurtosis within acceptable limits. Univariate and multivariate outliers were examined; values greater than three standard deviations from the mean were Winsorized. Tests of multicollinearity indicated that none of the variables were correlated above .90. Independent variables were not transformed given that the current approaches are highly robust to non-normality (Cohen, Cohen, West, & Aiken, 2003).

Moderation and mediation analyses were conducted using the PROCESS macro for SPSS (Hayes, 2012). To test the primary hypothesis, that anxiety would moderate the relationship between ASD severity and quality of life, two separate moderation models were evaluated using PROCESS model 1 (basic moderation). Specifically, anxiety was entered as a moderator of the

relationship between ASD severity and the social and psychological domains of the WHOQOL-BREF. In both models, categorical variables for language use (i.e., language use is completely normal, difficulties with pragmatic or social language, difficulties expressing needs) and anxiety medication status were entered as covariates.

To test the secondary hypothesis that there may be a significant indirect effect of anxiety implicated in the relationship between ASD severity and quality of life, PROCESS model 4 (basic mediation) was used. Two separate analyses were conducted. First, we evaluated the indirect effect of ASD severity on the dependent variable of the social domain of the WHOQOL-BREF through anxiety symptoms. The second model evaluated the indirect effect of ASD severity on the psychological domain of the WHOQOL-BREF through the anxiety symptoms. Once again, language use and medication for anxiety were entered as covariates.

In addition to the primary and secondary aims, we attempted to further characterize the extent and nature of anxiety symptoms among adult samples with ASD. Prevalence was examined through parent-report and self-report versions of the SCARED, with items upward extended for use in adult samples. Presence of clinically significant anxiety symptoms was determined by number of individuals exceeding cutoff scores on the SCARED total score, as well as cutoffs for subscales including panic, GAD, separation anxiety, SAD, and school avoidance. Additional items in the survey inquired about presence of comorbid anxiety diagnoses delivered by a professional, and parent perception of interference from anxiety symptoms, both currently and while the individual was an adolescent.

## **Results**

Descriptive statistics were computed for all demographic variables. In terms of level of functioning, the majority of respondents indicated that their adult used spoken language, though

with frequent endorsement of items related to difficulty with social or pragmatic use of language. First diagnoses reported commonly included Pervasive Developmental Disorder-Not Otherwise Specified ( $n = 94$ , 38%; PDD-NOS), Autistic Disorder ( $n = 68$ , 27%), or Asperger's syndrome ( $n = 66$ , 27%) per DSM-IV-TR (APA, 2000). Demographic data collected also included information regarding education, employment, independent living, use of federal or state benefits or services, and treatments/interventions that were used. Descriptive statistics for these variables suggested that the individuals about whom surveys were completed had approximately average cognitive ability and impairment from ASD symptoms, and moderate levels of independence (e.g., at least a high school education, a substantial portion with some type of employment). See Table 1 for full demographic results.

### **Parent- and Self-Reported Anxiety Symptoms**

Prior to regression analyses, we examined descriptive data to further characterize anxiety symptoms in our sample. All parents completed the SCARED, modified for use with an adult sample. Parents reported moderate levels of anxiety for their adults ( $M = 19.61$ ,  $SD = 13.04$ ). The proportion of individuals exceeding clinical cutoffs on any subscale of the SCARED ranged from 19% to 32%. See Tables 3 and 4 for full descriptive statistics regarding number of individuals exceeding clinical cutoffs on SCARED subscales, including tests of significant differences in quality of life for groups above and below cutoffs. The majority of parents completing items endorsed that anxiety was a current problem for their son or daughter (65%) and that anxiety had been a significant problem between the ages of 12-17 (80%). Additionally, 46% of all respondents reported that their adult had been formally diagnosed with an anxiety disorder at some point during their lifetime. The self-report sample also completed the SCARED. Similar patterns were evident across parent- and self-report samples in terms of proportion of

individuals exceeding clinical cutoffs in each subscale. Specifically, in the parent-report sample, the subscale with the greatest proportion of individuals exceeding cutoffs was SAD, followed by school avoidance, GAD, separation, and panic. For the self-report sample, the greatest proportion of individuals exceeded the clinical cutoff on the SAD subscale, followed by GAD, separation, school avoidance, and panic.

### **Anxiety as a Moderator of Quality of Life**

To explore our aim of anxiety as a moderator of the relationship between ASD severity and quality of life, regressions were run using PROCESS model 1. ASD severity and anxiety were entered in the first step of the regression analysis, and the interaction term between these two predictors was entered in the second step. In the first step, language and medication use were again entered as covariates. The initial model (i.e., with covariates and ASD severity as predictors) explained approximately 4% of the variance in quality of life in the social domain,  $F(3, 220) = 2.98, p = .03$ . In the next step, the main effect of anxiety was found to add significantly to the variance explained by the initial model,  $\Delta R^2 = .04, F(4,219) = 4.59, p = .003$ . The full model with the interaction of ASD severity and anxiety predicted approximately 9% of the variance in the social relations domain of the WHOQOL-BREF,  $F(5,218) = 4.52, p < .001$ . The addition of the interaction term explained significantly more variance than the previous model,  $\Delta R^2 = .02, F(1,218) = 3.98, p = .047$ . Thus, a significant moderating effect of anxiety was present for the relationship between ASD severity and quality of life in the social domain. Simple slopes for the association between ASD severity and social quality of life for low (one standard deviation below the mean), moderate (mean) and high (one standard deviation above the mean) levels of anxiety. Simple slope tests revealed that the ASD severity significantly

predicted quality of life at low levels of anxiety ( $\beta = -.24, p = .02$ ), but not at moderate ( $\beta = -.11, p = .18$ ) or high ( $\beta = .02, p = .86$ ) levels of anxiety.

The same regression model was run with psychological quality of life as a dependent variable (see Figure 2). Covariates were again entered in the first step of the regression. The initial model, with covariates and ASD severity entered as predictors, explained approximately 7% of the variance in the psychological domain of quality of life,  $F(3,220) = 6.88, p < .001$ . Adding the main effect of anxiety significantly added to the explained variance,  $\Delta R^2 = .14, F(4,219) = 16.27, p < .001$ . When the interaction term was added, the model did not explain significantly more variance,  $\Delta R^2 = .009, F(1,218) = 2.60, p = .11$ , suggesting that a moderating effect was not present for quality of life in the psychological domain. Despite the nonsignificant result, simple slope tests were used to probe the association between ASD severity and quality of life in the psychological domain at low, moderate, and high levels of anxiety. ASD severity significantly predicted quality of life at low ( $\beta = -.26, p = .004$ ) and moderate ( $\beta = -.17, p = .02$ ) levels of anxiety, but not at high levels of anxiety ( $\beta = -.07, p = .47$ ).

### **Indirect Effects of ASD on Quality of Life through Anxiety**

To explore the potential indirect effects of ASD severity on quality of life through anxiety, two mediation models were run. The first model evaluated the indirect effect of ASD severity on the social domain of the WHOQOL-BREF through anxiety symptoms (Figure 3). Figure 1 displays the test of simple mediation and the unstandardized coefficients of each pathway (Process Model 4), with use of spoken language and use of medication for anxiety symptoms entered as covariates. The overall model accounted for 7.7% of the variance in the social domain of the WHOQOL-BREF,  $F(4,219) = 4.59, p = .001$ . There was a significant total direct effect of ASD severity on the social domain of quality of life (path c) prior to entering the

hypothesized mediator,  $t = -2.50$ ,  $p = .01$ . Unstandardized indirect effects were tested using bootstrapping procedures, and effects were computed for each of 5,000 bootstrapped samples. The indirect effect was  $-.15$ , and the 95% confidence interval ranged from  $-.30$  to  $-.05$ ; given that the interval does not include zero, the effect was significant. Additionally, with anxiety entered in the model, the direct effect of ASD severity on social quality of life was no longer significant,  $t = -1.55$ ,  $p = .12$ , providing additional evidence for an indirect effect of ASD severity on quality of life, via anxiety.

The second model assessed the indirect effects of ASD severity on the psychological domain of the WHOQOL-BRE through anxiety (see Figure 4). Language use and anxiety medication were again entered as covariates. The overall model accounted for 22.9% of the variance in the psychological domain of the WHOQOL-BREF,  $F(4,219) = 16.27$ ,  $p < .001$ . There was a significant total direct effect (path c) of ASD severity on social quality of life prior to entering anxiety in the model,  $t = -4.14$ ,  $p < .001$ . Significance of indirect effects was again tested through the use of bootstrapping procedures, and effects were calculated for each of 5,000 bootstrapped samples. There was a significant indirect effect of anxiety,  $-.23$ , with a confidence interval of  $-.37$  to  $-.12$ . In this case, the direct effect remained with the mediator present,  $t = -2.43$ ,  $p = .02$ .

## Discussion

The goal of this study was to better understand the role of anxiety as it relates to quality of life among young adults with ASD. Our primary hypothesis, that total anxiety symptoms would moderate the relationship between ASD severity and social and psychological domains of quality of life, was partially supported. The addition of the interaction term of ASD severity and anxiety significantly increased the proportion of variance explained in quality of life in the social

domain. However, we did not identify a similar moderating relationship when the psychological domain of quality of life was used as a dependent variable. However, for both the social and psychological domains, anxiety contributed significantly to the variance explained by the models, above and beyond the predictive value of language use, medication, and ASD severity. The broad nature of the constructs assessed as dependent variables may have further implications for the results of the current study. The psychological domain of the quality of life measure used in the current study incorporates a substantial number of topics, including bodily image and appearance, negative and positive feelings, self-esteem, spirituality and religion, and thinking, learning, memory, and concentration.

In contrast, the social relation domain focuses only on personal relationships, social support, and sexual activity (World Health Organization, 1998). While some of the constructs assessed in the psychological domain are likely to be impacted by anxiety symptoms in adults with ASD (e.g., positive and negative feelings, thinking, learning, memory, and concentration), other components of this domain of quality of life may be unrelated to the manifestation of anxiety in ASD. Still others may serve as protective factors (e.g., religion and spirituality). Symptoms assessed by the social relations subscale more likely map directly onto core deficits of ASD and are consistent with literature reporting high levels of loneliness and low levels of social support in adults with ASD (Howlin et al., 2004; Mazurek, 2014).

The current results also suggest that future research should explore the relative contributions of different domains of anxiety to quality of life. Specifically, the SAD subscale had the greatest proportion of individuals exceeding the clinical cutoff for both parent- and self-report samples (36% and 54%, respectively). Such a result is consistent with literature establishing SAD among the most commonly diagnosed anxiety disorders in cognitively



unimpaired individuals with ASD (White et al., 2009). Additionally, the finding that anxiety symptoms impact social quality of life provides preliminary support for models implicating unsuccessful social encounters in the development of anxiety symptoms, with ultimate effects on quality of life (Wood & Gadow, 2010). In this manner, some individuals, including those with greater levels of social motivation, genetic risk, or comorbid symptoms apart from anxiety, may be more likely to develop anxiety symptoms than others, and experience poorer outcome as a result. This moderating model merits further exploration in large and diverse samples, as well as in longitudinal research.

In addition to the identification of a significant moderating effect of anxiety, our hypotheses predicting a significant indirect effect of ASD symptom severity on quality of life through anxiety symptoms were supported. Significant indirect effects were found for both the social relations and psychological domains. Although the cross-sectional nature of the data in the current study precludes true mediation analysis, these results offer a competing hypothesis to the moderation model. In such a model, greater levels of ASD symptoms would result in higher levels of ASD-related stress, and ultimately anxiety symptoms, with deleterious effects on outcome (Wood & Gadow, 2010).

Ancillary to our primary aim of evaluating the impact of anxiety symptoms on quality of life, data collected in the current study advance the extant literature characterizing anxiety in samples of adults with ASD. Our results suggested that clinically elevated SAD and GAD were highly prevalent as evaluated by both parent- and self-report. The current parent-report sample provides data on a substantially larger sample of adults than previous studies of anxiety in adults with ASD (Lugnenard et al., 2011; Maddox & White, 2015). Both parent- and self-report data in the current study indicated rates of clinically elevated anxiety symptoms that are comparable to

established prevalence of anxiety among children and adolescents (van Steensel, Bogels, & Perrin, 2011). These results must be interpreted with an abundance of caution, as the use of a measure designed for children and adolescents in an adult sample is likely to subject these results to substantial error. However, it should be noted that the clinical cutoffs for both parent- and adult-report samples were established using normed samples of children and adolescents up to age 18 (e.g., Birmaher et al., 1997). Overlap in age between the normative sample and the sample used in the current study was present in that approximately 10% of the adults in the current study were age 18, and nearly half (47%) were 22 or younger. The single set of cutoffs for children and adolescents established in the normative sample have not been evaluated for use in early adulthood, but the possibility exists that items designed for children and adolescents may lose some of their utility when applied to the current sample (e.g., “I follow my mother or father wherever they go”). The exclusion of these items may actually *decrease* the score necessary to exceed the cutoff and increase the proportion of adults reporting clinical levels of anxiety. Future work establishing rates of anxiety in epidemiological samples of adults with ASD will be necessary prior to making broad conclusions regarding the potential for these symptoms to impact quality of life or overall outcomes.

The results described above should be considered within the context of the sample for the current study. Demographic results suggested that all participants were relatively homogenous with regard to age and ethnicity, and generally came from families where parents had completed at least a college education. In terms of reported educational attainment, employment status, and language use, the distribution of the sample was broadly representative of previous studies of outcomes in adults with ASD (e.g., Taylor & Seltzer, 2011). The similarity of this sample to those in other studies examining similar constructs provides initial support for generalizability of

results; that is, symptoms of anxiety may well play a role in determining outcome for individuals at a variety of levels of functioning.

The non-longitudinal nature of the data collected in the current study precluded the use of true mediation analyses. The overuse of mediation analyses with cross-sectional data is well-documented, and researchers have been found to argue frequently for identification of a causal mechanism where none can exist without collection of longitudinal data (e.g., Maxwell & Cole, 2007). Given that no previous studies have examined the role of comorbid symptomatology in outcomes for adults with ASD, identification of preliminary evidence that anxiety may impact quality of life using cross-sectional data is essential prior to conducting a longitudinal study. The results of the current study should thus be considered a first necessary step in the identification of the role of anxiety in adults with ASD, rather than a proposal that a mechanism has been identified.

### **Limitations**

The results of the current study should be interpreted in light of the study's limitations. First, the sample of the current study was restricted in age range and homogenous in terms of ethnicity. High levels of education (i.e., 80% of parent respondents with a bachelor's degree or higher) were also overrepresented among parent respondents. Additionally, demographic data were collected retroactively, due to inadvertent omission of those questions in the initial survey. In part, the homogeneity present may be reflective of the nature of an elective participation sample who have documented a vested interest in research participation through their registration with IAN. Additional limitations as a result of recruitment through IAN include an inability to independently verify diagnoses of adults with ASD and a limited ability to characterize the cognitive ability of respondents. While IAN ensures that all individuals enrolled in the registry

have a diagnosis provided by a professional, the use of best-practice diagnostic measures among professionals varies widely. A small number of parents providing comments upon completion of the survey reported that items pertaining to anxiety (i.e., the SCARED) were difficult to assess for their adult given that individual's limited cognitive or verbal ability.

Limited availability of ASD-specific, parent-report measures for the constructs of interest further limits interpretation and generalization of these results. Specifically, a valid and reliable measure to assess anxiety of an adult via parent- or other-report does not exist, requiring the upward extension of a measure designed for child and adolescent use. Although the majority of the items in the SCARED likely map well onto anxiety symptoms as they manifest in adulthood, specific subscales (e.g., separation anxiety, school avoidance) are likely to have limited applicability to adults or to function differently in ASD samples. The level of functioning in our sample likely also played a role in parents' ability to report on their adult's internalizing symptoms. The majority of parent respondents indicated that their adults used spoken language, held at least a high school diploma, and frequently worked, were enrolled in school full-time, or lived somewhat independently. For adults with this level of cognitive ability and independence, contact with their parents may be sufficiently limited so as to preclude their having a complete understanding of anxiety and depressive symptoms.

### **Future Directions**

Despite these noted limitations, our results provide several avenues for further study of these constructs in this population. Perhaps most critical is a longitudinal examination of the impact of anxiety on outcomes in adults with ASD. While the current study included a limited attempt to determine whether anxiety symptoms were present earlier in development, identification of the mechanistic role of anxiety necessitates collection of data on these variables

throughout development. Such a study might well seek to rely more heavily on self-report data, for which a broader array of reliable and valid measures for anxiety exist.

Another of the study's aims, to further establish the prevalence of anxiety symptoms in adults with ASD, merits further exploration. While the current study expands upon the limited empirical evidence for widespread prevalence of anxiety among adults by finding the same trend in a larger sample, use of a single parent/self-report measure to determine presence of clinically significant symptoms of anxiety limits the validity of the results. Future research should aim to identify true rates of anxiety disorders among adults with ASD using self- and other-report measures as well as clinical interviews administered by trained clinicians.

## **Conclusion**

Despite the current study's exploratory nature and noted limitations, our results offer several implications for the study of comorbidity of anxiety and ASD and potential impacts on quality of life. The moderating effect of anxiety identified in the current study provides preliminary evidence for a new factor contributing to the historically poor outcomes typically seen in adults with ASD. While core ASD symptoms, cognitive ability, and adaptive functioning remain among the strongest predictors for high quality of life, anxiety likely plays a meaningful role, particularly among individuals with greater cognitive ability. Given the shared etiology of ASD and anxiety and the potential for ASD symptoms to confer increased risk for development of anxiety disorders, the relationship between these two symptom domains in adults must be further clarified. If, as hypothesized, anxiety serves as a barrier to the achievement of high quality of life and positive outcome in adults with ASD, the development and evaluation of ASD-specific treatments targeting anxiety symptoms in adults offers potential for facilitating

increased independence, decreasing public health costs, and improving functional outcomes of adults with ASD.

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**Table 1.** *Demographics of Adults with ASD, as Reported by Parents*

Variable	<i>n</i>	%
<b>Gender</b>		
Male	160	82.05
Female	35	17.95
<b>Ethnicity</b>		
White	181	92.82
Black	5	2.56
Latino	4	2.05
Asian	4	2.05
Other	5	2.56
<b>Age of diagnosis</b>		
Before 3	77	31.05
Age 3-5	86	34.68
Age 6-7	39	15.73
Later than 7	46	18.55
<b>Language use</b>		
Typical use	56	22.76
Pragmatic/social difficulties	115	46.75
Difficulty expressing needs	72	29.27
<b>Level of Education</b>		
Less than high school	65	26.42
High school diploma/GED	101	41.06
Some college	51	20.73
Associate's degree	11	4.47
Bachelor's degree	14	5.69
Variable	N	M(SD)
Child age	195	21.77 (3.10)
Parent age	191	54.26 (6.31)

**Table 2.** *Descriptive Statistics*

	<i>n</i>	Minimum	Maximum	Mean ( <i>SD</i> )	Skewness	Kurtosis
Parent Report						
SRS Total T Score	230	44	92	70.09 (9.80)	-.24	-.32
SCARED Panic	241	0	23	3.46 (3.97)	1.53	2.80
SCARED GAD	241	0	18	5.51 (.68)	.68	-.52
SCARED Separation	241	0	15	2.76 (2.88)	1.50	2.38
SCARED Social	241	0	14	6.33 (4.10)	.21	-.91
SCARED School Avoid	241	0	8	1.56 (1.90)	1.21	.59
SCARED Total	241	0	58	19.62 (13.04)	.77	-.06
QoL Psychological	236	20.83	100	65.02 (16.08)	-.01	-.41
QoL Social Relations	236	0	100	50.67 (20.22)	-.21	.62
Self-Report						
SCARED Panic	41	0	23	5.56 (6.50)	1.20	.26
SCARED GAD	41	0	18	8.34 (4.88)	.16	-.40
SCARED Separation	41	0	16	4.29 (4.24)	1.03	.43
SCARED Social	41	0	14	7.59 (4.47)	-.07	-1.25
SCARED School Avoid	41	0	8	2.00 (2.28)	.88	-.33
SCARED Total	41	3.00	77	27.78 (18.19)	.65	-.15
QoL Psychological	37	0	100.00	63.63 (17.91)	-.89	3.44
QoL Social Relations	37	0	83.33	49.55 (25.45)	-.66	-.77



**Table 3.** *Proportion of Individuals Exceeding Cutoffs on SCARED*

	Parent Report ( <i>n</i> = 241) <i>n</i> (%) above cutoff	Self-Report ( <i>n</i> = 41) <i>n</i> (%) above cutoff
SCARED Panic	46 (19.50)	13 (31.70)
SCARED GAD	58 (24.58)	19 (46.30)
SCARED Separation	47 (19.92)	16 (39.00)
SCARED Social	86 (36.44)	22 (53.70)
SCARED School	61 (25.85)	15 (36.60)
SCARED Total	76 (32.30)	20 (48.80)

**Table 4.** WHOQOL Mean Scores by Cutoff on Parent-Reported SCARED

	Social QoL below cutoff	Social QoL above cutoff	<i>t</i>	Psych QoL below cutoff	Psych QoL above cutoff	<i>t</i>
SCARED Panic	51.93 (19.70)	45.47 (21.71)	1.96*	67.98 (15.53)	52.81 (12.14)	6.18**
SCARED GAD	52.81 (19.49)	44.11 (21.17)	2.89**	68.24 (15.41)	55.17 (14.08)	5.72**
SCARED Separation	51.15 (19.64)	48.76 (22.52)	.72	66.98 (15.64)	57.18 (15.58)	3.85**
SCARED Social	51.33 (20.02)	49.52 (20.63)	.66	67.50 (16.06)	60.71 (15.27)	3.18**
SCARED School	53.33 (19.53)	43.03 (20.37)	3.51**	68.64 (15.41)	54.64 (13.29)	6.32**
SCARED Total	53.80 (18.45)	44.08 (22.23)	3.54**	69.51 (15.05)	55.59 (14.04)	6.78**

*Note.* \*  $p < .05$ ; \*\*  $p < .01$

**Table 5. Correlation Table**

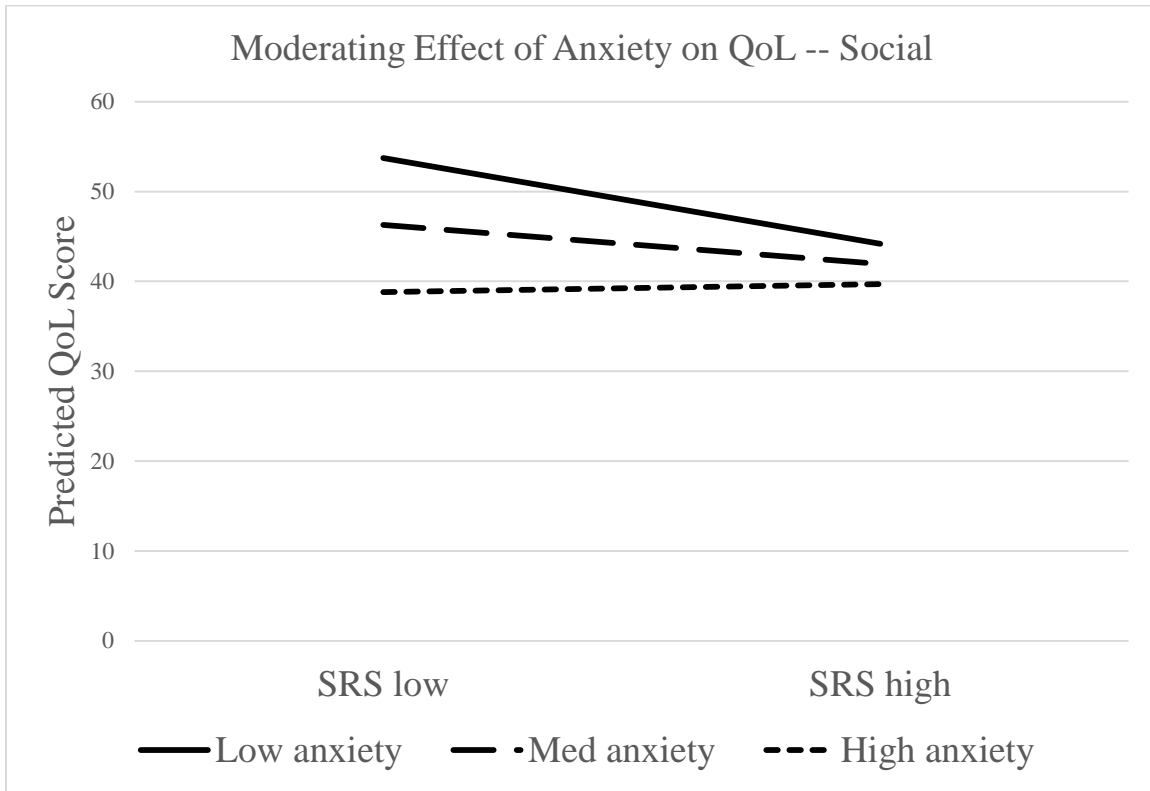
	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. SRS Total	--								
2. SCARED Panic	.21**	--							
3. SCARED GAD	-.18**	.52**	--						
4. SCARED Separation	.28**	.53**	.36**	--					
5. SCARED Social	.23**	.42**	.35**	.38**	--				
6. SCARED School	.08	.59**	.53**	.49**	.48**	--			
7. SCARED Total	.15*	.81**	.77**	.70**	.71**	.77**	--		
8. WHOQOL-BREF Social	-.14*	-.19**	-.25**	-.14*	-.05	-.22**	-.22**	--	
9. WHOQOL-BREF Psychological	-.22**	-.42**	-.42**	-.33**	-.23**	-.43**	-.48**	.52**	--

Note. \*  $p < .05$  (2-tailed), \*\*  $p < .01$  (2-tailed).

**Table 6. Correlations of Parent- and Adult-report Measures**

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
1. Panic (self)	--															
2. GAD (self)	.66*	--														
3. Separation (Self)	.73*	.50*	--													
4. Social (self)	.40*	.63*	.36*	--												
5. School (self)	.72*	.49*	.61*	.52*	--											
6. Total (self)	.89*	.84*	.79*	.71*	.78*	--										
7. QoL Psych (self)	-	-	-	-.38*	-	-	--									
8. QoL Social (self)	.54*	.60*	.43*		.45*	.61*		--								
9. Panic (parent)	-.27	-.15	-.08	.01	-.32	-.19	.44*		--							
10. GAD (parent)	.52*	.15	.46*	.16	.59*	.45*	-.19	-.23		--						
11. Separation (parent)	.38*	.42*	.20	.16	.29	.37*	-.16	-.30	.43*		--					
12. Social (parent)	.27	-.11	.59*	.08	.46*	.29	.03	-.08	.67*	.27		--				
	.15	.17	.15	.55*	.31	.31	.05	.27	.41*	.19	.37*		--			

13. School (parent)	.29	.03	.45*	.19	.47*	.32*	-.10	-.11	.76*	.48*	.75*	.45*	--			
14. Total (parent)	.44*	.20	.48*	.31	.56*	.47*	-.10	-.12	.87*	.64*	.78*	.65*	.87*	--		
15. QoL Psych (parent)	-.34*	-.23	-.36*	-.08	-.28	-.33*	.38*	.55*	-.34*	-	-.19	-.01	-.34*	-.34*	--	
16. QoL Social (parent)	-.18	-.14	-.23	.05	-.11	-.16	.10	.52*	-.22	-.31*	-.16	.07	-.18	-.21	.68*	--

**Figure 1. Moderation Effects for Social Relations domain of WHOQOL-BREF**

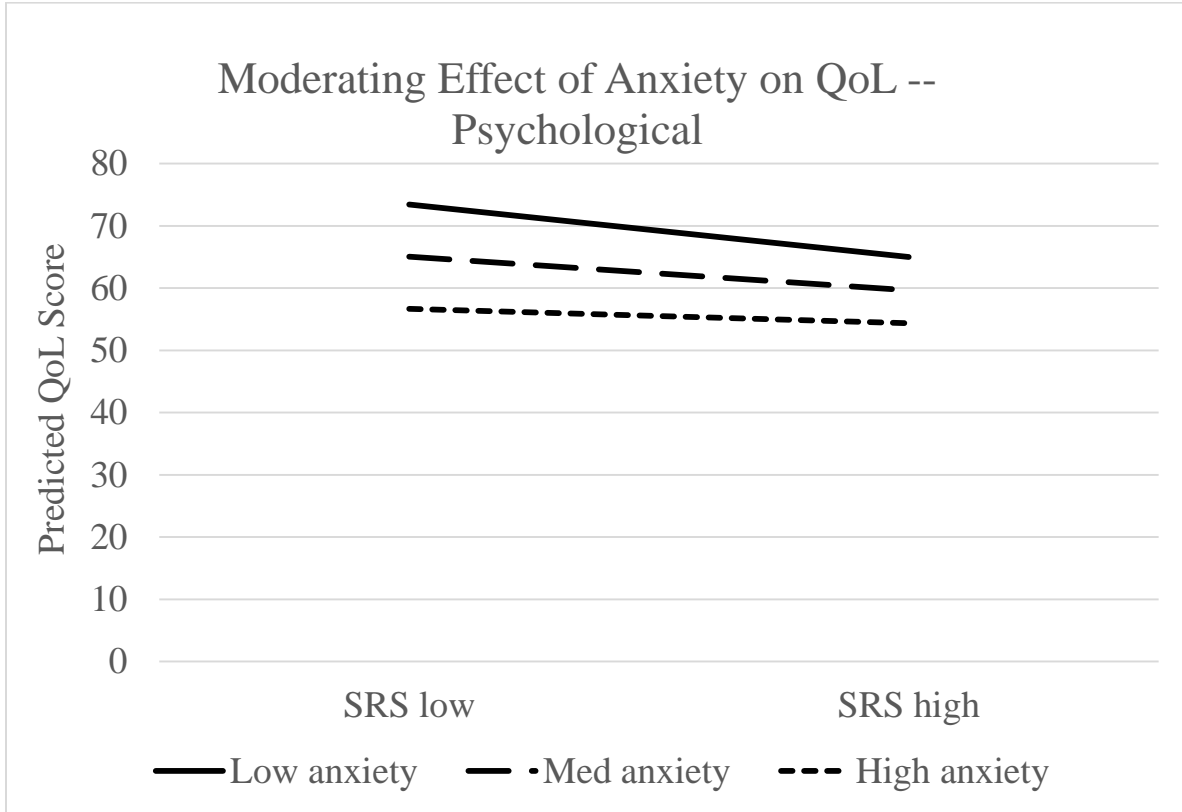
**Figure 2. Moderation Effects for Psychological domain of WHOQOL-BREF**

Figure 3. Indirect Effects Model for Social Relations Domain of WHOQOL-BREF

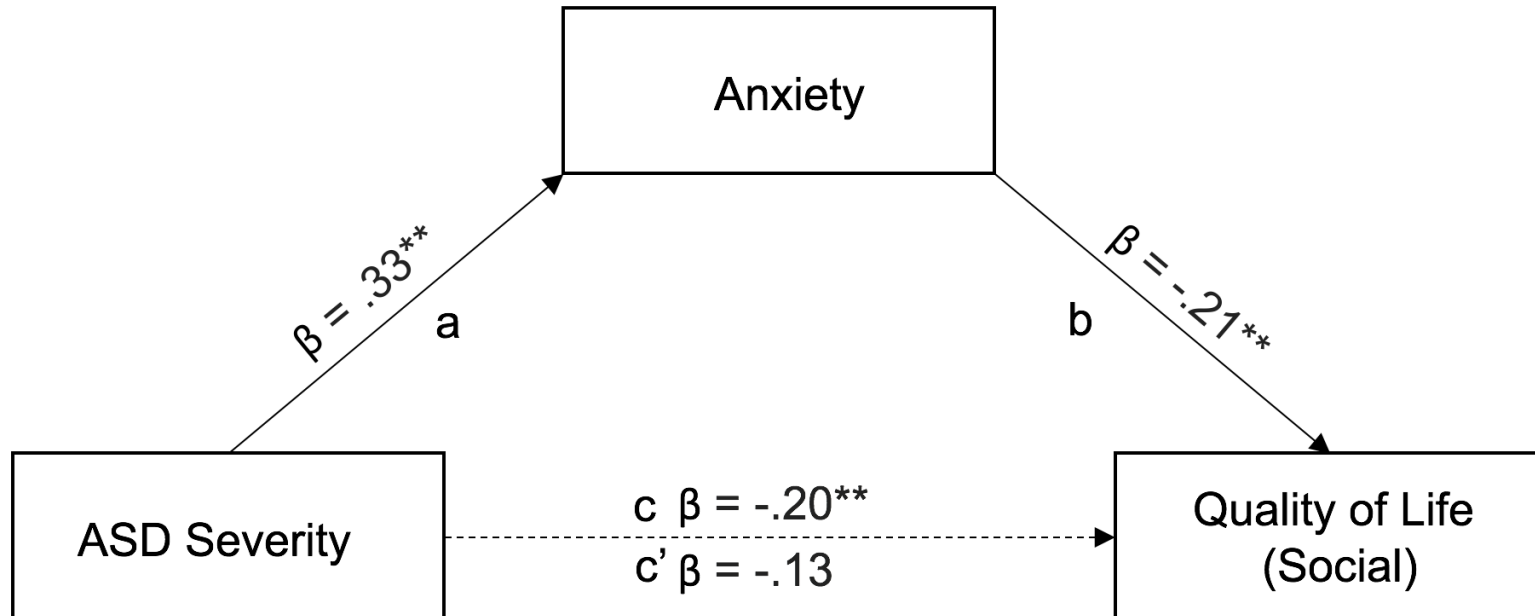
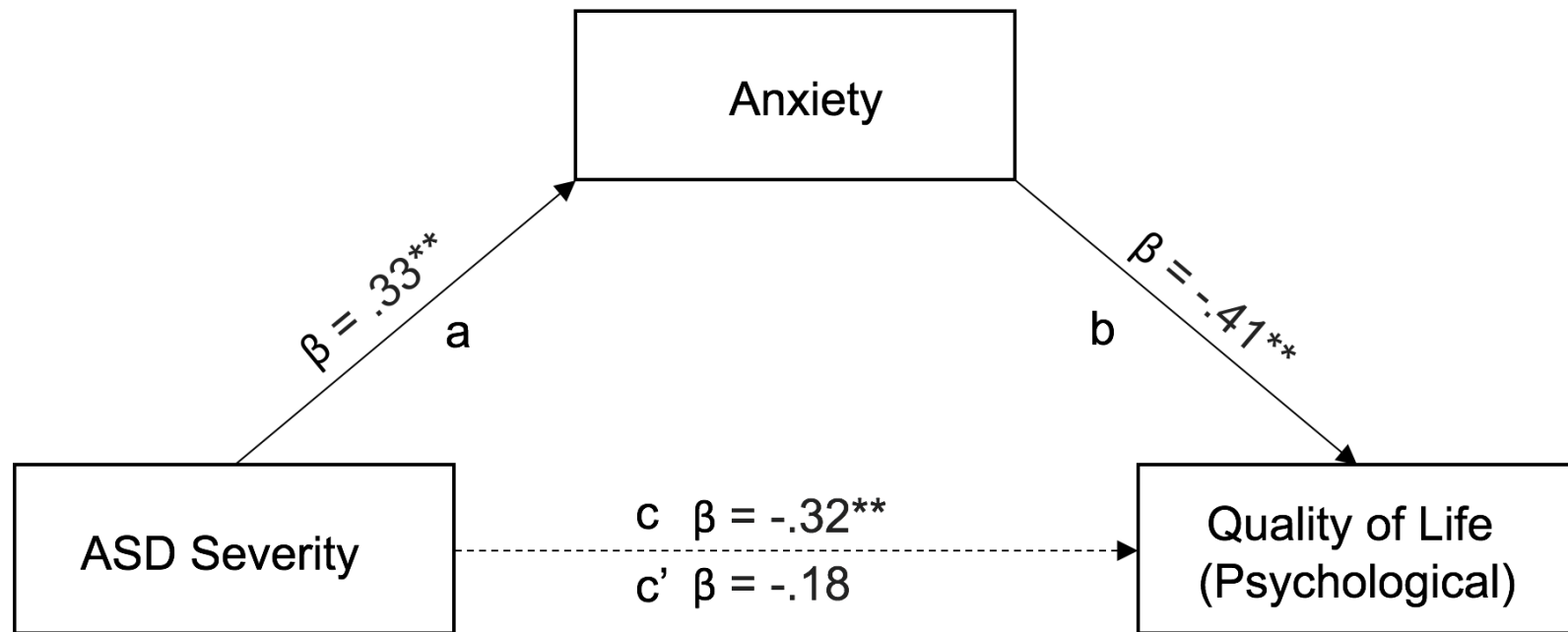




Figure 4. Indirect Effects Model for Psychological domain of WHOQOL-BREF



## Appendix A. IRB Approval Letter



**Office of Research Compliance**  
 Institutional Review Board  
 North End Center, Suite 4120, Virginia Tech  
 300 Turner Street NW  
 Blacksburg, Virginia 24061  
 540/231-4606 Fax 540/231-0959  
 email [irb@vt.edu](mailto:irb@vt.edu)  
 website <http://www.irb.vt.edu>

### MEMORANDUM

**DATE:** April 18, 2016  
**TO:** Susan Williams White, Isaac Smith, Thomas H Ollendick  
**FROM:** Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)  
**PROTOCOL TITLE:** Exploring the Mechanistic Role of Anxiety in the Experience of Adverse Outcomes among Adults with ASD  
**IRB NUMBER:** 15-1140

Effective March 14, 2016, the Virginia Tech Institution Review Board (IRB), at a convened meeting, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

<http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

### PROTOCOL INFORMATION:

Approved As: **Full Review**  
 Protocol Approval Date: **March 14, 2016**  
 Protocol Expiration Date: **March 13, 2017**  
 Continuing Review Due Date\*: **February 27, 2017**

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

### FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

*Invent the Future*

## **Appendix B: Consent Forms**

### **Anxiety and Outcomes in Adults with ASD**

#### Investigators:

Principal investigator: Susan W. White, PhD, Associate Professor

Co-Investigator: Isaac Smith, Graduate Student

Psychology Department, Virginia Tech

#### Purpose

The purpose of this study is to evaluate anxiety symptoms in adults with ASD and to determine the extent to which these symptoms impact the achievement of positive outcomes, as measured by pursuit of postsecondary education, competitive employment, independent living skills, financial independence, and ratings of quality of life.

#### Procedure

For this survey, you will be asked to complete a series of questions about your adult child's behaviors, feelings, and experiences. Please read each question carefully and try to answer each question to the best of your ability. It is estimated that it will take approximately 30-40 minutes to complete these questions. If you choose to participate, you will be directed to a secure website to complete the survey. Following your participation, you will be provided with a link to a shorter survey that you have the option to share with your adult child. He or she may complete this short survey if they are willing and able.

#### Risks and Benefits

This survey should not take a great deal of time to complete, but it is time that you could spend doing other activities. It is also possible that the types of questions we are asking in the survey could make you feel uncomfortable. If the questions are too distressing for you, please remember that you can stop at any time. There is no immediate and direct benefit to you for completing this survey. However, we hope that results of this project can help inform services that could ultimately help adults with ASD achieve greater levels of independence and quality of life. No promises or guarantees of benefits have been made to encourage you to participate.

#### Costs and Payment for Participation

Following completion of the survey, you will have the opportunity to participate in a raffle as a token of our appreciation for your participation. We will give away approximately 70 Amazon gift cards valued at \$25.00 each. We can't predict exactly how many individuals will enroll and take the survey, but we estimate a 1 in 9 chance of winning a gift certificate. You will be asked to provide your email so that we may contact raffle winners.

#### Confidentiality

We ask for only a limited amount of personally identifying information in this survey (your email address). The email address is requested ONLY for the raffle and it is not associated with your survey responses. Beyond this we ask for no other information, such

as your name or birthdate, so as to ensure as much confidentiality as possible. Your e-mail address, which is necessary to conduct the raffle, will be kept secure and not shared outside of this study. Subject numbers will be assigned for data storage. All of your answers will be kept *strictly confidential*. If you would like to contact a member of the research team or the lab that is sponsoring this study, you are welcome to do so. Contact information is at the bottom of this document.

It is possible that the Institutional Review Board (IRB) may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research. If you would like to contact the graduate student conducting this study or her advisor, you are welcome to do so. Contact information is at the bottom of this page.

You do not have to participate in this survey and if you choose to participate, you can stop at any time. We do ask, however, that you try to answer every question completely to the best of your ability.

Any identifiable information that is obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by U.S. or State law.

#### Questions/Contact Information

If you have any questions about the protection of human research participants regarding this study, you may contact Dr. David Moore, Chair Virginia Tech Institutional Review Board for the Protection of Human Subjects, telephone: (540) 231-4991; email: [moored@vt.edu](mailto:moored@vt.edu); address: Office of Research Compliance, 2000 Kraft Drive, Suite 2000 (0497), Blacksburg, VA 24060 or David W. Harrison, PhD, Chair Departmental Institutional Review Board, telephone: (540) 231-4422 ; e-mail: [dwh@vt.edu](mailto:dwh@vt.edu).

If you would like to speak with a member of this research team, please call the Psychosocial Interventions Lab at (540) 231-6744 or email Isaac Smith and Susan White at [psyc.soc.interventions@gmail.com](mailto:psyc.soc.interventions@gmail.com) and [icsmith@vt.edu](mailto:icsmith@vt.edu).

**Your completion of this online survey will indicate that you consent to participate in this study.**

**We appreciate your input. Thank you for your time and help in this study!**

## **Anxiety and Outcomes in Adults with ASD**

### Investigators:

Principal investigator: Susan W. White, PhD, Associate Professor

Co-Investigator: Isaac Smith, Graduate Student

Psychology Department, Virginia Tech

### Purpose

The purpose of this study is to evaluate anxiety symptoms in adults with ASD and to determine the extent to which these symptoms impact the achievement of positive outcomes, as measured by pursuit of postsecondary education, competitive employment, independent living skills, financial independence, and ratings of quality of life.

### Procedure

For this survey, you will be asked to complete a series of questions about your behaviors, feelings, and experiences. Please read each question carefully and try to answer each question to the best of your ability. It is estimated that it will take approximately 20 minutes to complete these questions. If you choose to participate, you will be directed to a secure website to complete the survey.

### Risks and Benefits

This survey should not take a great deal of time to complete, but it is time that you could spend doing other activities. It is also possible that the types of questions we are asking in the survey could make you feel uncomfortable. If the questions are too distressing for you, please remember that you can stop at any time. There is no immediate and direct benefit to you for completing this survey. However, we hope that results of this project can help inform services that could ultimately help adults with ASD achieve greater levels of independence and quality of life. No promises or guarantees of benefits have been made to encourage you to participate.

### Costs and Payment for Participation

Following completion of the survey, you will have the opportunity to participate in a raffle as a token of our appreciation for your participation. We will give away approximately 70 Amazon gift cards valued at \$25.00 each. We can't predict exactly how many individuals will enroll and take the survey, but we estimate a 1 on 9 chance of winning a gift certificate. You will be asked to provide your email so that we may contact raffle winners.

### Confidentiality

We ask for only a limited amount of personally identifying information in this survey (your email address). The email address is requested **ONLY** for the raffle and it is not associated with your survey responses. Beyond this we ask for no other information, such as your name or birthdate, so as to ensure as much confidentiality as possible. Your e-mail address, which is necessary to conduct the raffle, will be kept secure and not shared outside of this study. Subject numbers will be assigned for data storage. All of your answers will be kept *strictly confidential*. If you would like to contact a member of the

research team or the lab that is sponsoring this study, you are welcome to do so. Contact information is at the bottom of this document.

It is possible that the Institutional Review Board (IRB) may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research. If you would like to contact the graduate student conducting this study or her advisor, you are welcome to do so. Contact information is at the bottom of this page.

You do not have to participate in this survey and if you choose to participate, you can stop at any time. We do ask, however, that you try to answer every question completely to the best of your ability.

Any identifiable information that is obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by U.S. or State law.

#### Questions/Contact Information

If you have any questions about the protection of human research participants regarding this study, you may contact Dr. David Moore, Chair Virginia Tech Institutional Review Board for the Protection of Human Subjects, telephone: (540) 231-4991; email: [moored@vt.edu](mailto:moored@vt.edu); address: Office of Research Compliance, 2000 Kraft Drive, Suite 2000 (0497), Blacksburg, VA 24060 or David W. Harrison, PhD, Chair Departmental Institutional Review Board, telephone: (540) 231-4422 ; e-mail: [dwh@vt.edu](mailto:dwh@vt.edu).

If you would like to speak with a member of this research team, please call the Psychosocial Interventions Lab at (540) 231-6744 or email Isaac Smith and Susan White at [psyc.soc.interventions@gmail.com](mailto:psyc.soc.interventions@gmail.com) and [icsmith@vt.edu](mailto:icsmith@vt.edu).

**Your completion of this online survey will indicate that you consent to participate in this study.**

**We appreciate your input. Thank you for your time and help in this study!**

## Appendix C: Online Survey – Demographic Questions

2. What was the FIRST autism spectrum disorder (ASD) diagnosis your son/daughter ever received from a professional? (If it has not changed, this is the ASD diagnosis he or she has now.)

- Autism or Autistic disorder
- Asperger's Syndrome
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder (PDD) (choose only if none of the above apply)
- Autism Spectrum Disorder (ASD) (choose only if none of the above apply)
- My son/daughter never has been diagnosed with an autism spectrum disorder by a professional.
- Other (please specify in the box below)

If you selected "other", please describe here.

3. Please provide the approximate age of your son/daughter at the time he/she was diagnosed.

- Before age 3
- Age 3-5
- After age 5, but before 3rd grade (approx. age 6-7)
- After 3rd grade, but before middle school (approx. age 8-10)
- Middle school (approx. age 11-13)
- High school (approx. age 14-18)
- After high school (18+)
- Don't know/can't remember

4. Who gave your son/daughter this FIRST ASD diagnosis?

- Physician
- Psychiatrist
- Clinical Psychologist
- Team of health professionals
- Team of professionals in a school system
- Don't know/remember
- Other

If you selected "other", please describe here.

5. Is your son/daughter's CURRENT ASD diagnosis different than the first?

- Yes, the CURRENT diagnosis is different.
- No, the CURRENT diagnosis is the same.



6. What is your son/daughter's CURRENT ASD diagnosis?

- Autism or Autistic disorder
- Asperger's Syndrome
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder (PDD) (choose only if none of the above apply)
- Autism Spectrum Disorder (ASD) (choose only if none of the above apply)

7. Who gave your son/daughter this CURRENT ASD diagnosis?

- Physician
- Psychiatrist
- Clinical Psychologist
- Team of health professionals
- Team of professionals in a school system
- Don't know/remember
- Other

If you selected "other", please describe here.

8. Does your son/daughter use spoken language?

- No  
 Yes

9. Describe your son/daughter's use of spoken language.

- Language use is completely typical.  
 There are difficulties mainly with "pragmatic" or social language (e.g., using eye contact and facial expressions in conversations, speaking differently with a child vs. an adult, providing background information to someone entering a conversation).  
 There is difficulty expressing needs using spoken language.  
 Other

If you selected "other", please describe here.

10. Does your son/daughter use any of the following to help him or her communicate? Check all that apply.

- Sign language or other nonverbal means of communication without aid of technology  
 High-tech assistive technology (such as a voice-output communication device, keyboard, etc.)  
 Low-tech assistive technology (such as Picture Exchange Communication system, Flip-and-Talk, etc.)  
 Communication by gesture or behavior  
 None of the above  
 Other

If you selected "other", please describe here.

11. What is the highest level of education your son/daughter has completed?

- Less than high school
- High school graduate or equivalent (GED)
- Some college but no degree
- Associate's degree
- Vocational/technical or trade certification
- Bachelor's degree
- Master's degree
- Ph.D. or Professional degree
- Other

If you selected "other", please describe here.

12. Is your son/daughter currently attending school, such as high school, vocational or trade school, or college?

- No
- Yes

13. With whom does your son/daughter live? Check all that apply.

- With a spouse or other life partner
- With his or her own children
- With housemates or friends that he or she got to choose
- With parents
- With one or more siblings
- With a relative other than parents, siblings, or children (such as a grandparent, aunt, or uncle)
- With paid caregivers
- Lives alone
- Other

If you selected "other", please describe here.

14. Does your son/daughter currently have paid employment?

No

Yes

15. On average, how many hours per week does your son/daughter work?

- 0-9 hours
- 10-19 hours
- 20-29 hours
- 30-39 hours
- 40+ hours

16. What is your son/daughter's current work situation? Check all that apply.

- My son/daughter does not work
- Regular employment (with no help or support)
- Supported employment (he or she may have a job coach or other special help at work)
- Sheltered workshop
- Enclave employment (he or she may work in a business with a group of other people with special needs, all under supervision of an agency serving people with disabilities)
- Day program that includes work or vocational activities
- Internship or work study program
- Other

If you selected "other", please describe here.

17. Would your son/daughter like to work more hours than he or she is currently able to get?

- No
- Yes

18. You have told us your son/daughter is not working. Please help us understand his/her situation. Check all that apply.

- Unemployed--wants to work but can't find work
- Has tried to work but faced discrimination or other difficulties with employers because of ASD
- Does not wish to work at present (may be in school, stay-at-home parent, etc.)
- Not able to work because it would interfere with federal or state benefits (such as disability payments)
- Not able to work because the workplace would be too challenging (because of ASD or other physical or mental health issues)
- Other

If you selected "other", please describe here.

19. How much of his/her own financial support (not counting any disability or subsidized support) does your son/daughter provide?

- My son/daughter does not provide any of his/her own financial support
- My son/daughter provides less than half of his/her own financial support
- My son/daughter provides about half of his/her own financial support
- My son/daughter provides more than half of his/her own financial support

20. Does your son/daughter receive any federal or state benefits, such as Social Security Disability Insurance (SSDI) or Medicaid?

- Yes
- No

21. What federal or state benefits does your son/daughter currently receive? Check all that apply or "none" if none apply.

- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- State disability programs that use only state and/or local funds
- Medicaid (for health insurance)
- Medicare
- Medicaid HCBS (Home and Community Based Services) waiver or Developmental Disability waiver
- Employment assistance or job support (sometimes called "Vocational Rehabilitation" or "VR")
- Section 8 housing
- Transportation services for people with disabilities
- None
- Other

If you selected "other", please describe here.

22. Has your son/daughter been diagnosed with any of the following conditions by a professional? Check all that apply.

- A seizure disorder or epilepsy
- Asthma
- Diabetes
- Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)
- Oppositional Defiant Disorder (ODD)
- Obsessive Compulsive Disorder (OCD)
- Anxiety (such as social phobia, generalized anxiety disorder, panic disorder, or some other kind of anxiety)
- Depression (such as major depressive disorder, seasonal affective disorder, postpartum depression, or some other kind of depression)
- Bipolar disorder
- Schizophrenia
- None
- Other

If you selected "other", please describe here.



23. What treatments or interventions is your son/daughter currently using to help with ASD or other conditions he or she might have, such as attention deficit hyperactivity disorder (ADHD) or anxiety? Check all that apply.

- Medication
- Alternative medicine (herbs, homeopathic remedies, acupuncture, vitamins, etc.)
- Individual therapy or counseling (for example, talk therapy or cognitive behavioral therapy)
- Group therapy
- Marital or family therapy
- Support group, in person
- Support group, online
- Spiritual practice (such as prayer or meditation)
- Speaking with a pastor, rabbi, etc.
- Self-help books
- Applied Behavior Analysis (ABA)
- Physical therapy
- Occupational therapy
- Speech and language therapy
- Social skills training or a social skills group
- Life skills or self-care training
- None
- Other

If you selected "other", please describe here.

24. Does your son/daughter have close acquaintances/friends?

- No
- Yes, 1 friend
- Yes, 2-5 friends
- Yes, 5+ friends

25. Please help characterize your son/daughter's relationships with acquaintances/friends. Check all that apply.

- Friendship is mutual, i.e., both parties initiate spending time together
- Friend participates in shared enjoyed activities with my son/daughter
- None of the above

26. When your son/daughter was in middle and high school (approximate ages 12-17), was anxiety a significant problem? Anxiety could include intense fears, persistent worry about a number of different areas, or fearfulness in social situations.

- Yes
- No

27. Is anxiety a significant problem currently?

- Yes
- No

28. In your opinion, what most helps your son/daughter alleviate worry or anxiety? Please be as specific as possible (e.g., anxiety medication, psychotherapy, exercise, meditation, etc.)

29. Please provide the approximate age of your son/daughter at the time you became concerned about his/her anxiety.

- Before age 3
- Age 3-5
- After age 5, but before 3rd grade (approx. age 6-7)
- After 3rd grade, but before middle school (approx. age 8-10)
- Middle school (approx. age 11-13)
- High school (approx. age 14-18)
- After high school (18+)
- Don't know/can't remember

### Appendix D. SRS-2 (Relative/Other Report)



John N. Const...jo, MD

Assessment ID

SRS-2 AutoScore™ Form

Adult (Relative/Other Report)

MALE

FEMALE

Rated individual's name \_\_\_\_\_ Age in years \_\_\_\_\_

Rater's name \_\_\_\_\_ Date of rating \_\_\_\_\_

Relationship to rated individual  Mother  Father  Other relative  
 Spouse  Other

**INSTRUCTIONS**

For each question, please darken the circle that best describes this individual's behavior over the past 6 months.

**PLEASE PRESS HARD WHEN MARKING YOUR RESPONSES.**

1 = NOT TRUE    2 = SOMETIMES TRUE    3 = OFTEN TRUE    4 = ALMOST ALWAYS TRUE

1. Seems much more uncomfortable in social situations than when alone. .... 1 2 3 4
2. Expressions on his or her face don't match what he or she is saying. .... 1 2 3 4
3. Seems self-confident when interacting with others. .... 1 2 3 4
4. When under stress, he or she shows rigid or inflexible patterns of behavior that seem odd. .... 1 2 3 4
5. Doesn't recognize when others are trying to take advantage of him or her. .... 1 2 3 4
6. Would rather be alone than with others. .... 1 2 3 4
7. Is aware of what others are thinking or feeling. .... 1 2 3 4
8. Behaves in ways that seem strange or bizarre. .... 1 2 3 4
9. Seems too dependent on others for help with meeting basic needs. .... 1 2 3 4
10. Takes things too literally and doesn't get the real meaning of a conversation. .... 1 2 3 4
11. Has good self-confidence. .... 1 2 3 4
12. Is able to communicate his or her feelings to others. .... 1 2 3 4
13. Is awkward in turn-taking interactions with others (for example, doesn't seem to understand the give-and-take of conversations). .... 1 2 3 4
14. Is not well coordinated. .... 1 2 3 4
15. Recognizes and appropriately responds to changes in other people's tone of voice and facial expressions. .... 1 2 3 4
16. Avoids eye contact or has unusual eye contact. .... 1 2 3 4
17. Recognizes when something is unfair. .... 1 2 3 4
18. Has difficulty making friends, even when trying his or her best. .... 1 2 3 4
19. Gets frustrated trying to get ideas across in conversations. .... 1 2 3 4
20. Shows unusual sensory interests (for example, smelling his or her fingers frequently) or strange, repetitive ways of handling or manipulating small items within reach. .... 1 2 3 4
21. Is able to imitate others' actions and demeanor when it is socially appropriate to do so. .... 1 2 3 4
22. Interacts appropriately with other adults. .... 1 2 3 4
23. Does not join group activities or social events unless forced to do so. .... 1 2 3 4
24. Has more difficulty than others with changes in his or her routine. .... 1 2 3 4
25. Doesn't seem to mind being out of step with or "not on the same wavelength" as others. .... 1 2 3 4
26. Offers comfort to others when they are sad. .... 1 2 3 4
27. Avoids starting social interactions with other adults. .... 1 2 3 4
28. Thinks or talks about the same thing over and over. .... 1 2 3 4
29. Is regarded by others as odd or weird. .... 1 2 3 4
30. Becomes upset in a situation with lots of things going on. .... 1 2 3 4
31. Can't get his or her mind off something once he or she starts thinking about it. .... 1 2 3 4
32. Has good personal hygiene. .... 1 2 3 4

Continue on back page

PLEASE PRESS HARD WHEN MARKING YOUR RESPONSES.

1 = NOT TRUE    2 = SOMETIMES TRUE    3 = OFTEN TRUE    4 = ALMOST ALWAYS TRUE

33. Is socially awkward, even when trying to be polite. .... ① ② ③ ④
34. Avoids people who want to be emotionally close to him or her. .... ① ② ③ ④
35. Has trouble keeping up with the flow of a normal conversation. .... ① ② ③ ④
36. Has difficulty relating to family members. .... ① ② ③ ④
37. Has difficulty relating to other adults. .... ① ② ③ ④
38. Responds appropriately to mood changes in others (for example, when a friend's mood changes from happy to sad). .... ① ② ③ ④
39. Has an unusually narrow range of interests. .... ① ② ③ ④
40. Is imaginative without losing touch with reality. .... ① ② ③ ④
41. Wanders aimlessly from one activity to another. .... ① ② ③ ④
42. Seems overly sensitive to sounds, textures, or smells. .... ① ② ③ ④
43. Enjoys and is competent with small talk (casual conversation with others). .... ① ② ③ ④
44. Doesn't understand how events relate to one another (cause and effect) the way other adults do. .... ① ② ③ ④
45. Generally gets interested in what others nearby are paying attention to. .... ① ② ③ ④
46. Has overly serious facial expressions. .... ① ② ③ ④
47. Laughs at inappropriate times. .... ① ② ③ ④
48. Has a sense of humor, understands jokes. .... ① ② ③ ④
49. Does extremely well at a few intellectual or computational tasks, but does not do as well at most other tasks. .... ① ② ③ ④
50. Has repetitive, odd behaviors. .... ① ② ③ ④
51. Has difficulty answering questions directly and ends up talking around the subject. .... ① ② ③ ④
52. Knows when he or she is talking too loud or making too much noise. .... ① ② ③ ④
53. Talks to people with an unusual tone of voice (for example, talks like a robot or like he or she is giving a lecture). .... ① ② ③ ④
54. Seems to react to people as if they are objects. .... ① ② ③ ④
55. Knows when he or she is too close to someone or is invading someone's space. .... ① ② ③ ④
56. Walks in between two people who are talking. .... ① ② ③ ④
57. Isolative; tends not to leave his or her home. .... ① ② ③ ④
58. Concentrates too much on parts of things rather than seeing the whole picture. .... ① ② ③ ④
59. Is overly suspicious. .... ① ② ③ ④
60. Is emotionally distant, doesn't show his or her feelings. .... ① ② ③ ④
61. Is inflexible, has a hard time changing his or her mind. .... ① ② ③ ④
62. Gives unusual or illogical reasons for doing things. .... ① ② ③ ④
63. Touches or greets others in an unusual way. .... ① ② ③ ④
64. Is too tense in social settings. .... ① ② ③ ④
65. Stares or gazes off into space. .... ① ② ③ ④

## Appendix E. Screen for Child Anxiety and Related Disorders

### Screen for Child Anxiety Related Disorders (SCARED) PARENT Version—Page 1 of 2 (to be filled out by the PARENT)

Developed by Boris Birmaher, M.D., Suneeta Khetarpal, M.D., Marlane Cully, M.Ed., David Brent, M.D., and Sandra McKenzie, Ph.D., Western Psychiatric Institute and Clinic, University of Pittsburgh (October, 1995). E-mail: birmaherb@upmc.edu

See: Birmaher, B., Brent, D. A., Chiappetta, L., Bridge, J., Monga, S., & Baugher, M. (1999). Psychometric properties of the Screen for Child Anxiety Related Emotional Disorders (SCARED): a replication study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(10), 1230-6.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

#### Directions:

Below is a list of sentences that describe how people feel. Read each phrase and decide if it is "Not True or Hardly Ever True" or "Somewhat True or Sometimes True" or "Very True or Often True" for your child. Then, for each statement, fill in one circle that corresponds to the response that seems to describe your child *for the last 3 months*. Please respond to all statements as well as you can, even if some do not seem to concern your child.

	0 Not True or Hardly Ever True	1 Somewhat True or Sometimes True	2 Very True or Often True	
1. When my child feels frightened, it is hard for him/her to breathe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
2. My child gets headaches when he/she am at school.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SH
3. My child doesn't like to be with people he/she doesn't know well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SC
4. My child gets scared if he/she sleeps away from home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SP
5. My child worries about other people liking him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	GD
6. When my child gets frightened, he/she feels like passing out.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
7. My child is nervous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	GD
8. My child follows me wherever I go.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SP
9. People tell me that my child looks nervous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
10. My child feels nervous with people he/she doesn't know well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SC
11. My child gets stomachaches at school.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SH
12. When my child gets frightened, he/she feels like he/she is going crazy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
13. My child worries about sleeping alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SP
14. My child worries about being as good as other kids.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	GD
15. When my child gets frightened, he/she feels like things are not real.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
16. My child has nightmares about something bad happening to his/her parents.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SP
17. My child worries about going to school.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SH
18. When my child gets frightened, his/her heart beats fast.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
19. He/she child gets shaky.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	PN
20. My child has nightmares about something bad happening to him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	SP

**Screen for Child Anxiety Related Disorders (SCARED)**  
**PARENT Version—Page 2 of 2 (to be filled out by the PARENT)**

	0 Not True or Hardly Ever True	1 Somewhat True or Sometimes True	2 Very True or Often True	
21. My child worries about things working out for him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>GD</b>
22. When my child gets frightened, he/she sweats a lot.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>PN</b>
23. My child is a worrier.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>GD</b>
24. My child gets really frightened for no reason at all.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>PN</b>
25. My child is afraid to be alone in the house.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SP</b>
26. It is hard for my child to talk with people he/she doesn't know well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SC</b>
27. When my child gets frightened, he/she feels like he/she is choking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>PN</b>
28. People tell me that my child worries too much.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>GD</b>
29. My child doesn't like to be away from his/her family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SP</b>
30. My child is afraid of having anxiety (or panic) attacks.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>PN</b>
31. My child worries that something bad might happen to his/her parents.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SP</b>
32. My child feels shy with people he/she doesn't know well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SC</b>
33. My child worries about what is going to happen in the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>GD</b>
34. When my child gets frightened, he/she feels like throwing up.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>PN</b>
35. My child worries about how well he/she does things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>GD</b>
36. My child is scared to go to school.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SH</b>
37. My child worries about things that have already happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>GD</b>
38. When my child gets frightened, he/she feels dizzy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>PN</b>
39. My child feels nervous when he/she is with other children or adults and he/she has to do something while they watch him/her (for example: read aloud, speak, play a game, play a sport).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SC</b>
40. My child feels nervous when he/she is going to parties, dances, or any place where there will be people that he/she doesn't know well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SC</b>
41. My child is shy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<b>SC</b>

**SCORING:**

A total score of  $\geq 25$  may indicate the presence of an **Anxiety Disorder**. Scores higher than 30 are more specific. **TOTAL =**

A score of 7 for items 1, 6, 9, 12, 15, 18, 19, 22, 24, 27, 30, 34, 38 may indicate **Panic Disorder** or **Significant Somatic Symptoms**. **PN =**

A score of 9 for items 5, 7, 14, 21, 23, 28, 33, 35, 37 may indicate **Generalized Anxiety Disorder**. **GD =**

A score of 5 for items 4, 8, 13, 16, 20, 25, 29, 31 may indicate **Separation Anxiety SOC**. **SP =**

A score of 8 for items 3, 10, 26, 32, 39, 40, 41 may indicate **Social Anxiety Disorder**. **SC =**

A score of 3 for items 2, 11, 17, 36 may indicate **Significant School Avoidance**. **SH =**

*The SCARED is available at no cost at [www.wpic.pitt.edu/research\\_under\\_tools\\_and\\_assessments](http://www.wpic.pitt.edu/research_under_tools_and_assessments), or at [www.pediatric\\_bipolar.pitt.edu/instruments](http://www.pediatric_bipolar.pitt.edu/instruments).*

March 27, 2012

## Appendix F. WHOQOL-BREF

### WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5



20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

**Do you have any comments about the assessment?**

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*[The following table should be completed after the interview is finished]*

	Equations for computing domain scores	Raw score	Transformed scores*	
			4-20	0-100
27. <b>Domain 1</b>	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ $\square + \square + \square + \square + \square + \square + \square$	a. =	b:	c:
28. <b>Domain 2</b>	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ $\square + \square + \square + \square + \square + \square$	a. =	b:	c:
29. <b>Domain 3</b>	$Q20 + Q21 + Q22$ $\square + \square + \square$	a. =	b:	c:
30. <b>Domain 4</b>	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ $\square + \square + \square + \square + \square + \square + \square + \square$	a. =	b:	c:

\* See Procedures Manual, pages 13-15

## Appendix G. Parent and self-report recruitment and reminder emails

IAN Subject Recruitment ID#: SR1137

Study Title: Anxiety and Outcomes Study (SR1137)

Email Subject Line: Online Study for Parents of ASD Adults: Anxiety and Outcomes

Link:

Dear @@RecipientFirstName @@RecipientLastName,

When you joined the Interactive Autism Network (IAN) Research Project, we promised to inform you about research projects that might be of interest to you. Researchers at Virginia Tech are conducting an online study regarding the extent to which anxiety impacts the achievement of positive outcomes in adults with ASD.

**Who qualifies?** Parents of young adult offspring (18-27 years) with ASD are invited to participate. One parent should respond per family. Parents should reside in the United States.

**What is involved?** Qualifying parents complete an anonymous online survey regarding symptoms of ASD and anxiety, as well as questions regarding education, employment, and daily living skills. The survey takes about 30-40 minutes and does not have to be completed in one sitting. In addition, parents who complete the survey will be provided with a link that they may choose to pass on to their adult children, who will then have the opportunity to complete a short additional survey (about 20 minutes) regarding their own experiences. Surveys can be accessed using any computer, tablet, or smart phone.

**Thank you!** Both parent and young adult respondents will be entered into a drawing for a \$25 gift card to Amazon (odds of winning 1 in 9). You will need to provide your email address in order to enter the drawing, but your email will not be associated with your responses. If you do provide your email address, you will also receive a report about the findings of the study upon its completion.

**Questions?** Please contact the Principal Investigator, Dr. Susan White, at [sww@vt.edu](mailto:sww@vt.edu) or the Graduate Assistant, Isaac Smith, at [icsmith@vt.edu](mailto:icsmith@vt.edu)

**This is an IAN 1-Click study! Please click on the appropriate link below to indicate whether or not you are interested in the study.** Once you have clicked on either the "Interested" or "Not Interested/Don't Qualify" link below, IAN will no longer send you notifications about this study.

**Interested?** Please click on this link to go to the participant contact form: @@URLLink

**Not Interested/Don't Qualify?** @@NotInterestedLink

*IAN Subject Recruitment ID: SR1137.* You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider

nor your standing as a participant in IAN Research. IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Krieger Institute. Please email [ResearchTeam@IANproject.org](mailto:ResearchTeam@IANproject.org) if you are no longer interested in receiving information about subject recruitment opportunities from IAN, or if you have any questions or concerns that you would like to share.

To: studyparticipant@email.com  
Subject: Anxiety and Outcomes Survey Code

Hello,

Thank you very much for your interest in our study! Below please find the 4-digit code you will enter on the first page of the survey:

Code: XXXX

The survey can be accessed at this link:

<https://www.surveymonkey.com/r/VTSurveyStart>

Contact information for questions is available on the first page of the above link.  
Your participation is greatly appreciated!

To: studyparticipant@email.com  
Subject: Reminder -- Invitation to Participate in Anxiety and Outcomes Survey

Hello,

Recently, you received an email inviting you to participate in a research study about your adult child with ASD through your participation in the Interactive Autism Network.

The study consists of a brief survey asking about your feelings and experiences, and should take no more than 45 minutes, after which you will be eligible to enter a raffle for \$25 Amazon gift cards.

Your responses would make an extremely valuable contribution to our body of knowledge about ASD in adulthood and could contribute to future programs or interventions in the ASD community.

As a reminder, below are the link to the survey and a 4-digit code you will enter to access the survey.

Code: XXXX

<https://www.surveymonkey.com/r/VTselfreport>

Contact information for questions is available on the first page of the above link. Your participation is greatly appreciated!

To: studyparticipant@email.com  
Subject: Final Reminder -- Anxiety and Outcomes Survey

Hello,

Recently, you received an email inviting you to participate in a research study about your adult child with ASD through your participation in the Interactive Autism Network.

Completing the study should take no more than 45 minutes, and details about the study and your compensation can be found in previous emails or by contacting the researcher.

Your responses would make an extremely valuable contribution to our body of knowledge about ASD in adulthood and could contribute to future programs or interventions in the ASD community.

Below are the link to the survey and a 4-digit code you will enter to access the survey.

Code: XXXX

<https://www.surveymonkey.com/r/VTselfreport>

This email will constitute our final reminder of our invitation for you to complete the survey. You will receive no further contact regarding this study.

Thank you very much!

To: studyparticipant@email.com  
Subject: Anxiety and Outcomes Survey – Brief additional question

Hello,

Recently, you participated in a research study about your adult child with ASD through your participation in IAN. Unfortunately, critical demographic information regarding your child was not initially collected as a part of the survey.

We are writing to respectfully request that you respond to this **extremely brief** addendum to our survey that should take **less than one minute** to complete. This data is essential for accurately describing our sample and ensuring that its results will generalize to families like yours.

Below is the link to the survey and a 4-digit code you will enter along with your response:

Code: XXXX

<https://www.surveymonkey.com/r/VTdemographic>

Thank you very much!

To: studyparticipant@email.com  
Subject: Anxiety and Outcomes Study Follow Up -- Reminder

Hello,

Recently, you were sent a request to complete an **extremely brief** (less than one minute) survey providing critical demographic information for a study you completed through your participation in IAN.

We are writing again with a gentle reminder that the information collected in this brief survey is essential to accurately describing our results and that your time commitment in completing it would be minimal.

Below are the link to the survey and a 4-digit code you will enter to access the survey.

Code: XXXX

<https://www.surveymonkey.com/r/VTSurveyStart>

If you complete this 5-item survey now, you will receive no further contact from our study. Participants not providing responses will be sent a final reminder within the next 5 days.

Contact information for questions is available on the first page of the above link. Your participation is greatly appreciated!



To: studyparticipant@email.com  
Subject: Final Reminder -- Anxiety and Outcomes Follow Up

Hello,

Within the past week, you were sent a reminder that we are seeking your assistance in providing critical demographic information as part of your participation in our Anxiety and Outcomes study.

The survey responses we are seeking are **extremely brief** and should take you less than one minute complete. They are essential to accurately describing our results and ultimately benefitting the ASD community.

Below are the link to the survey and a 4-digit code you will enter to access the survey.

Code: XXXX

<https://www.surveymonkey.com/r/VTselfreport>

This email will constitute our final reminder of our invitation for you to complete the survey. You will receive no further contact regarding this study.

Thank you very much!

To: studyparticipant@email.com

Subject: Invitation to Participate in Anxiety and Outcomes Survey

Hello,

Your parent or caregiver recently completed a survey for a research study through the Interactive Autism Network. Upon completing the study, they indicated that you may be willing to fill out a survey and answer some brief questions about your behaviors, feelings, and experiences.

The link below will take you to a page that provides more information about the study. If you choose to complete the survey, you will have the opportunity to participate in a raffle for \$25 Amazon gift cards as a token of our appreciation for your participation.

Below is a **4-digit code you will need to enter to access the survey** as well as the link to the survey:

Code: XXXX

<https://www.surveymonkey.com/r/VTselfreport>

Contact information for questions is available on the first page of the above link. Your participation is greatly appreciated!

To: studyparticipant@email.com  
Subject: Reminder -- Invitation to Participate in Anxiety and Outcomes Survey

Hello,

Recently, you received an email inviting you to participate in a brief study that your parent completed as part of their participation in the Interactive Autism Network.

The study consists of a brief survey asking about your feelings and experiences, and should take no more than 30 minutes, after which you will be eligible to enter a raffle for \$25 Amazon gift cards.

Your responses would make an extremely valuable contribution to our body of knowledge about ASD in adulthood and could contribute to future programs or interventions in the ASD community.

As a reminder, below are the link to the survey and a 4-digit code you will enter to access the survey.

Code: XXXX

<https://www.surveymonkey.com/r/VTselfreport>

Contact information for questions is available on the first page of the above link. Your participation is greatly appreciated!

To: studyparticipant@email.com  
Subject: Final Reminder -- Anxiety and Outcomes Survey

Hello,

Recently, you received an email inviting you to participate in a brief study that your parent completed as part of their participation in the Interactive Autism Network.

Details of the study can be found in previous emails or by contacting the researchers. Your responses would make an extremely valuable contribution to our body of knowledge about ASD in adulthood and could contribute to future programs or interventions in the ASD community.

Below are the link to the survey and a 4-digit code you will enter to access the survey.

Code: XXXX

<https://www.surveymonkey.com/r/VTselfreport>

This email will constitute our final reminder of our invitation for you to complete the survey. You will receive no further contact regarding this study.

Thank you very much!